NORTH DAKOTA DEPARTMENT of HEALTH

SAVING LIVES… ONE FOOT AT A TIME

Joyal Meyer, RN, MSN Katie Bentz, RN, BSN

North Dakota Newborn Screening Program

Objectives

- Understand the importance of newborn screening education and collection
- Identify the newborn screening process in North Dakota
- How to draw a newborn screening specimen
- Identify good and poor quality specimens
- Discuss transportation of the specimen and why timeliness is important

What is Newborn Screening and Why is it important?

- Testing is performed to detect life threatening and life altering medical conditions
- Screening most often occurs before symptoms appear
- Most babies with these disorders look and act like healthy normal newborns
- If detected early, newborn screening can save lives and improve the quality of life for babies
- Treatment is available for ***ALL*** the disorders screened, although it may be life long treatment
- Early treatment and identification helps to avoid:
  - Abnormal metabolism
  - Developmental delays which can cause brain damage
  - Coma and even death


Newborn Screening:
Saves or Improves the Lives of Over
12,000
Babies a Year!
PARENT EDUCATION
Obstetrician explains newborn screening process to expectant parents.
HOSPITAL SCREENING
Hospital nurse tests baby's hearing and heart, and collects blood from baby's heel.
LAB SCREENING
State public health lab tests baby's blood for at least 29 genetic conditions.
NORMAL RESULTS
Pediatrician reviews test results with parents at baby's first wellness visit.
POSITIVE RESULTS
Health Department staff calls pediatrician/parents to request re-testing baby. Medical specialists perform tests and make diagnosis.
FOLLOW-UP
Medical specialists and pediatrician develop a treatment plan and guide parents in caring for baby.

Newborn Screening Family Stories

https://www.youtube.com/watch?v=h8uh03wHGCs&t=3s

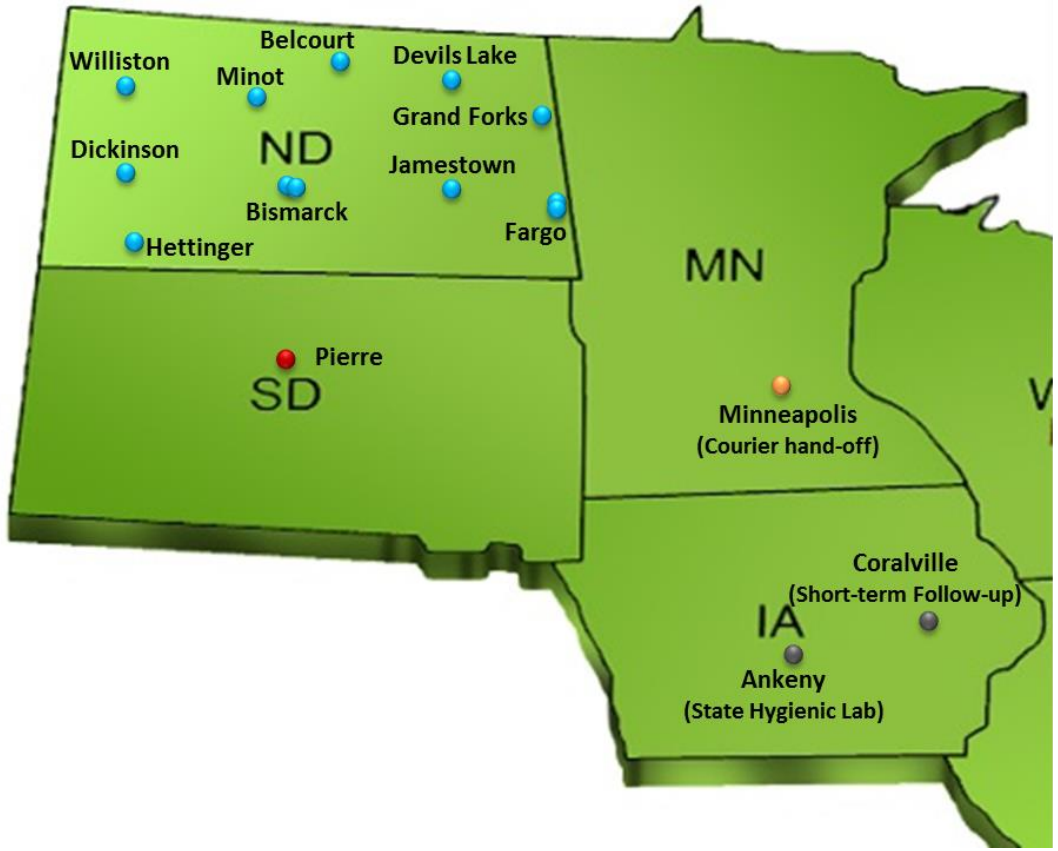
Partnering for Healthy Babies

- North Dakota Department of Health
  - Newborn Screening Program Administration
- University of Iowa State Hygienic Laboratory
- University of Iowa Children's Hospital
  - Short-term follow-up nurses
- North Dakota Hospitals and Clinics
- North Dakota Newborn Screening Advisory Committee
- Health Care Professionals
- Midwives/Doulas
- Parents/Families

Tri-state Collaborative

Partners include: ND, SD, and IA

- ND – estimated 13,000 births/year and 12 birthing hospitals
- SD - estimated 13,000 births/year and 26 birthing hospitals
- IA - estimated 40,000 births/year and 83 birthing hospitals



Cost for Newborn Screening

- ND NBS fee is $75 for the testing and specimen collectors are billed from the State Hygienic Laboratory in Iowa
- No cost for repeat testing
- Payment for the testing may be included with the specimen transport
  - *Check may be included from the midwife or parents*
- Supplies will need to be purchased by the collector
- For those collecting, where do you order your materials from?

University of Iowa Laboratory & Short Term Follow Up Services

- Iowa laboratory is open 365 days/year and processes labs daily
- ND NBS fee supports the services Iowa provides
- The ordering health care provider listed on the form will be called if screening is abnormal
- ***Only*** time critical disorders are called out on a weekend or holiday
- If NBS is calling you on a weekend/holiday, the baby requires intervention *that day* – not the next business day
- **Hours** make a difference in the outcome of a baby

HEADLINES

JOURNAL SENTINEL

A JOURNAL SENTINEL WATCHDOG REPORT

Deadly Delays

The nation's newborn screening programs depend on speed and science to save babies from rare diseases. But thousands of hospitals fall short, deadly delays are ignored and failures are hidden from public view — while babies and their families suffer.

Kristyna Wentz-Graff/Journal Sentinel

Delays at hospitals across the country undermine newborn screening programs, putting babies at risk of disability and death

By Ellen Gabler of the Journal Sentinel staff

Timeliness in Newborn Screening

Milwaukee Journal Sentinel published an article highlighting a lack of timeliness in newborn screening programs

"The nation's newborn screening programs depend on speed and science to save babies from rare diseases. But thousands of hospitals fall short, deadly delays are ignored and failures are hidden from public view — while babies and their families suffer."

Received the attention of the Health & Human Service Secretary

This article required newborn screening programs to review their *entire* system and look for ways to improve timeliness. *BABIES LIVES ARE AT STAKE*.

We now know that for the time critical disorders we screen for that EVERY. HOUR. COUNTS.

This is why the newborn screening lab and follow up staff work 365 days per year

Link to Article: http://archive.jsonline.com/watchdog/watchdogreports/Deadly-Delays-Watchdog-Report-Delays-at-hospitals-across-the-country-undermine-newborn-screening-programs-putting-babies-at-risk-of-disability-and-death-228832111.html

Aiden Cooper

Aiden's Newborn Screening Story

- Aiden couldn't keep formula down in the hospital – Doctors assured his mother he was fine and that she was just a first time mom
- After Aiden was discharged home, his stomach soon became swollen with bulging veins, he broke out in a rash, was limp, pale and wouldn't eat
- Infection raged through his tiny body as he lay in the NICU in Little Rock, AR
- Aiden's NBS was presumptive positive for Galactosemia – a time critical disorder
- Galactosemia prevented his body from digesting sugar in breast milk and formula; every time he ate he was being "poisoned"
- Once he was switched to a soy formula he improved, but the damage was already done

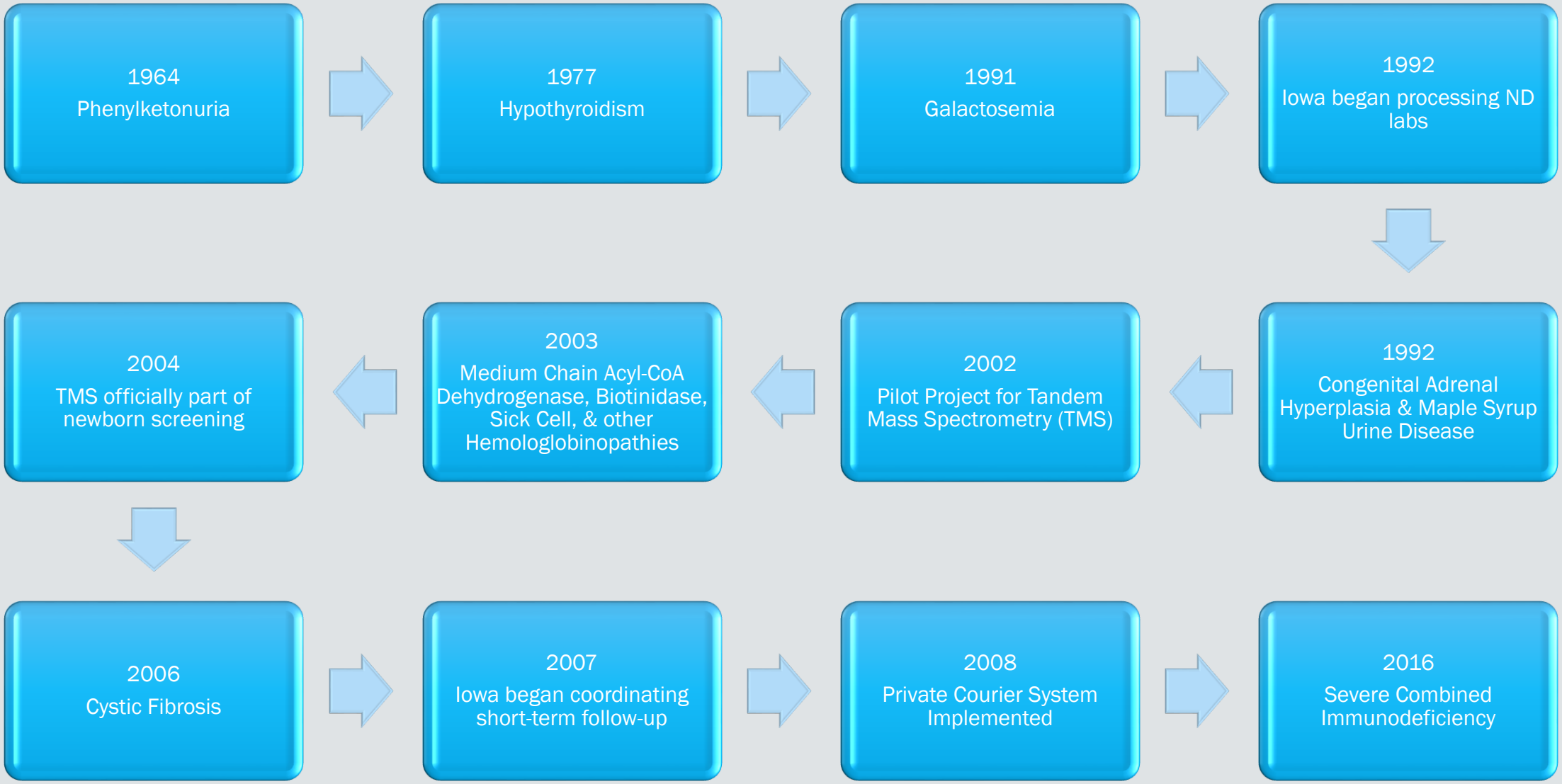
Aiden's Story – Continued

- At 3 years old, Aiden was only saying 2-3 words at once
- He walks unsteadily and has a hard time feeding himself because of his developmental delays
- Aiden needs speech, occupational and physical therapy
- Aiden's mother said "Every day is like a new battle for us"
- Aiden's NBS was collected on Day 2 of life (correct)
- Sample was not tested until *24 days* later – the specimen should be sent to the lab within 24 hours of collection

Key Points on Timeliness

- Collect the screen within *24 – 48 hours*
  - *the closer to 24 hours the better (but not before 24 hours unless baby is ill or going to be transferred to a hospital)*
- Do not wait to collect the screen until a 2 week follow up with mom/baby
- Specimens take at least ***3 hours*** to dry before packaging
- Send the specimen to the laboratory within *24 hours* of collection

History of ND Newborn Screening



Confirmed ND Newborn Screening Disorders

- 2011: 10,072 births (80 conditions detected by NBS)
- 2012: 11,503 births (87 conditions detected by NBS)
- 2013: 11,978 births (96 conditions detected by NBS)
- 2014: 12,840 births (115 conditions detected by NBS)
- 2015: 12,842 births (137 conditions detected by NBS)
- 2016: 13,027 births (156 conditions detected by NBS)

Statistics include traits identified through screening, not only disease

Most Common Disorders in ND ~ Past 5 Years

Congenital Hypothyroidism
42 cases

Incidence:
1/3,000 to 1/4,000

Cystic Fibrosis
13 cases

Incidence:
1/3,500 – Caucasians
1/17,000 – African Americans

Sickle Cell Anemia
9 cases

Incidence:
1/375 African Americans

Congenital Adrenal Hyperplasia
6 cases

Incidence:
1/15,000

Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)
4 cases

Incidence:
1/15,000

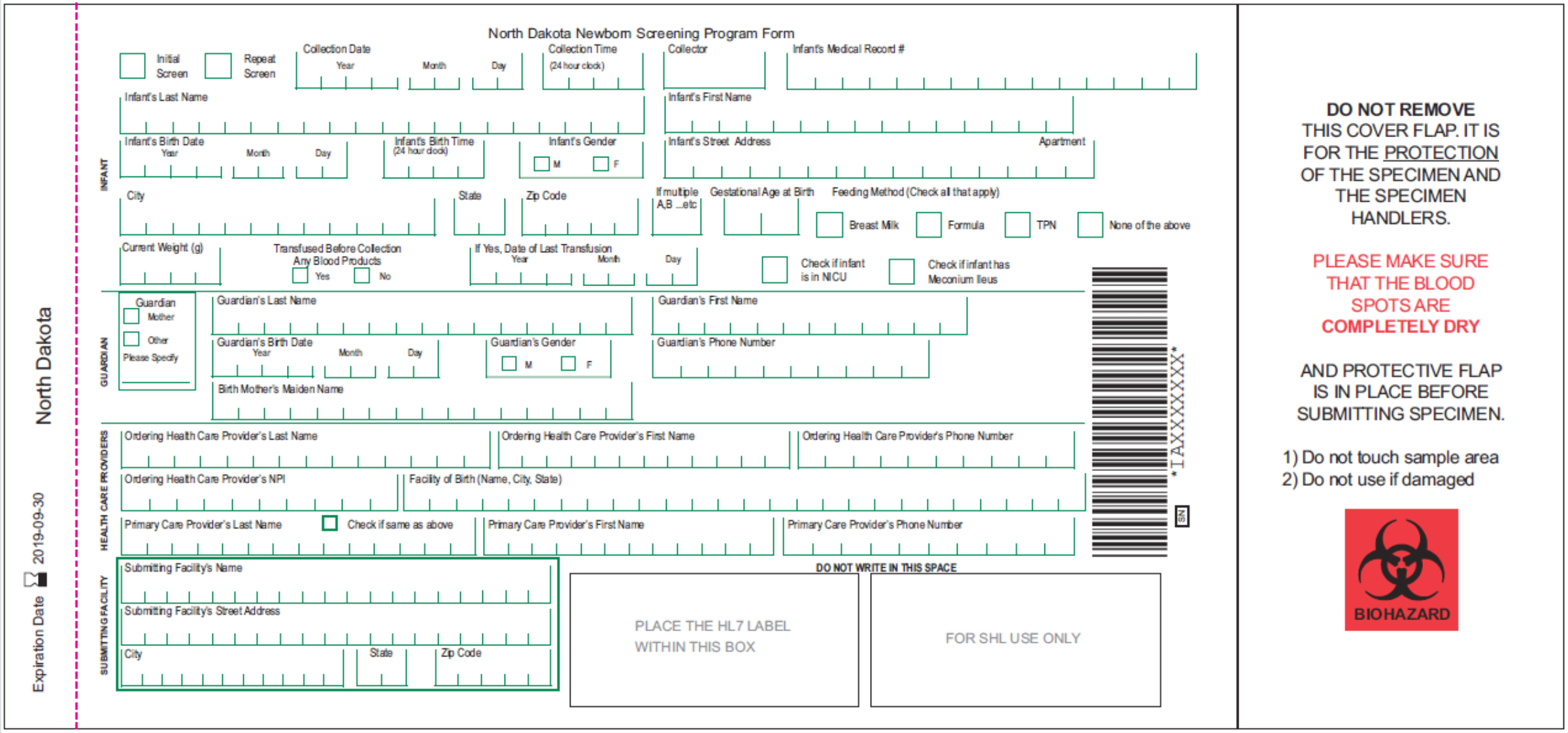
Classic Phenylketonuria (PKU)
3 cases

Incidence:
1/10,000 to 1/15,000

Biotinidase Deficiency
3 cases

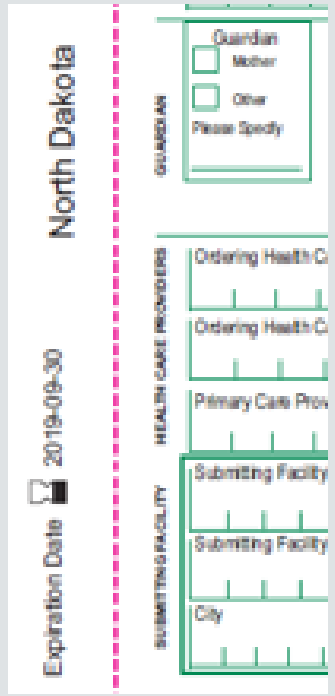
Incidence:
1/60,000

ND Blood Spot Card



Storage of Newborn Screening Dried Blood Spot Forms

- Clean and dry area
- Away from any direct sunlight
- Original wrapping
- Vertical position (avoids compression of the filter paper)
- Check the expiration date – shelf life 3 years



Every time you fill out a newborn screening form you hold a baby's life in your hands.

Fill out the form:

- ✓ Accurately
- ✓ Completely
- ✓ Legibly

If the test comes back presumptive positive, the information you provide is essential to locate the baby. It can be a matter of life and death.

It's not just a form – it's a baby

Missing Information on the Form

- Early Collection (EC) or Unknown Information
  - *Birth date or collection date or time missing*
  - *No results for tests affected by EC*

- Unknown weight
  - *Congenital Adrenal Hyperplasia results not reported*

- Transfusion status
  - *Must be marked no, not assumed no if blank*
  - *Transfusions affect results of the following conditions:*
    - Biotinidase
    - Galactosemia
    - Cystic Fibrosis
    - Hemoglobin Disorders

- Gestational Age
  - *SCID testing*

Early Collection

- Early Collection (<24 hrs) affects amino acid and endocrine results – invalid – no results reported,
  - ***NOTE: even a minute early can cause an invalid result on some testing***
  - *All early collections need to be repeated after 24 hrs*

- If baby is not doing well and needs to be transferred to a hospital, communicate with them a newborn screening has not been collected

- Communication is ***Key***

Materials Needed for NBS Collection

- Heel Warmer or Wash Cloth
- Alcohol Swabs - 70% Isopropyl Alcohol
- Lancet Device – 1.0 mm deep by 2.5 mm long
- Small Band-Aid
- Sterile Gauze – small 2X2
- Blood Spot Collection Form
- Powder/Latex Free Gloves

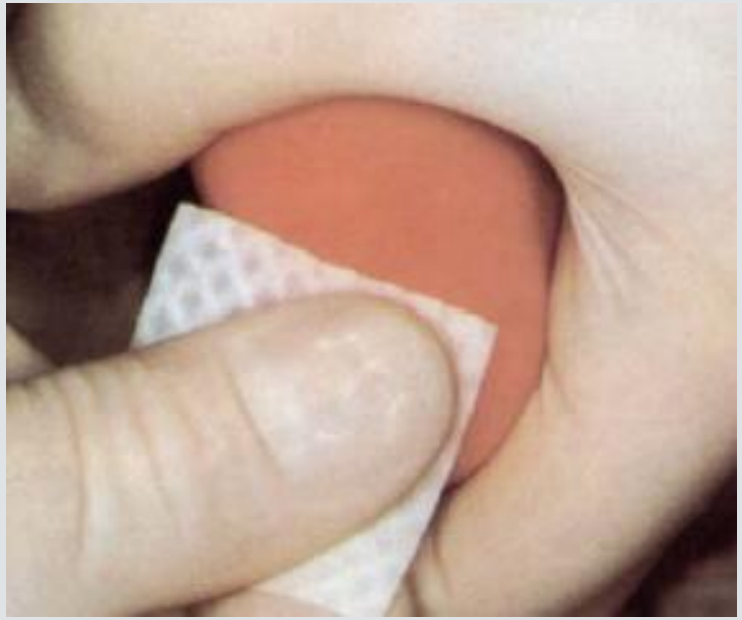
Prepare for collection by…

- Confirm infant's identity
- Wash hands
- Wear powder/latex free gloves
- Follow safety precautions when handling and disposing of sharps

Site Preparation

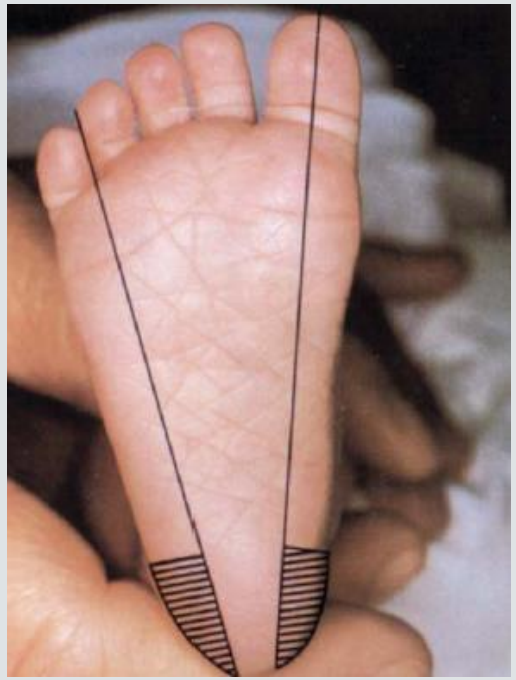
- Warm the newborn's heel by using:
  - Heel warming device
  - Soft cloth moistened with warm water (less than 42 ˚C) for 3-5 minutes
  - *Never* use a microwave to warm a wash cloth – may cause severe burns

Positioning Baby



- You may encourage the mother to nurse baby or a parent to hold them during the collection to keep baby more comfortable
- You may also wrap baby in a blanket with one leg left out to help position the baby
- Infant's leg should be lower than the heart
- Increases venous pressure
- Wipe heel with 70% isopropyl alcohol
- Air dry
  - *Important to let the alcohol dry completely before puncturing heel and applying blood to the filter paper*

Puncture and Collection Site



- Puncture in shaded area
- Plantar surface of the heel

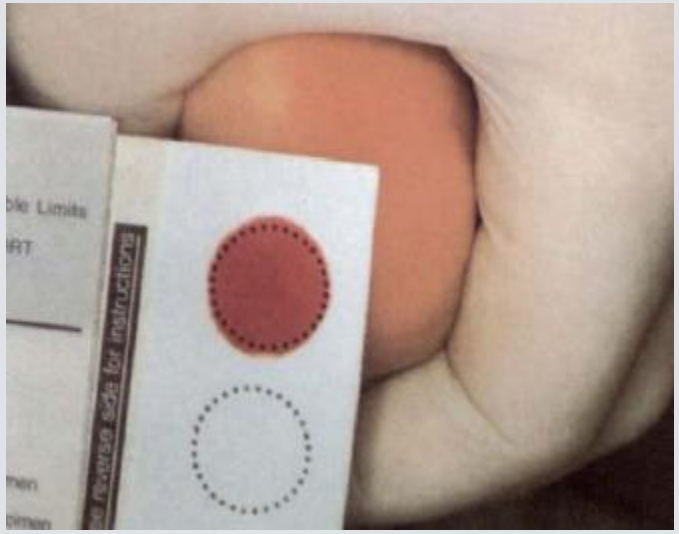
- Use sterile lancet - no scalpel blades or needles
- 1.0 mm deep by 2.5 mm long

Do *Not* Collect the Specimen in the following areas

- Arch of foot – could cause injury to nerves, tendons, and cartilage
- Fingers – even smallest lancet could reach infant's bone causing infection or gangrene
- Earlobe – could cause excessive bleeding
- Swollen or previously punctured site – accumulated fluid will contaminate the blood specimen

Direct Application

- Wipe away first drop of blood with sterile gauze
- Allow a ***large*** drop to form (50-75 µL)
  - *If you are unable to obtain a large drop you may intermittently apply gentle pressure to the heel, but no excessive "milking" or squeezing*
- Touch paper to blood ***ONCE*** and let soak through
- Apply ***ONE*** drop on each circle to only ***ONE SIDE***
- Continue and fill ***ALL*** circles
- Do ***NOT*** touch the heel to the filter paper



Take care of puncture site

- Elevate foot above the body
- Press sterile gauze or cotton swab against puncture site until bleeding stops
- Do not apply bandages that may damage baby's delicate skin

Quality Assurance

- Examine Blood Collection – take some time to look at the specimen and determine if it is a good quality
- Verify blood has soaked through both sides of the filter paper
  - *If blood did not soak through try again on another circle*
- Do ***not*** re-apply to same circle – this will cause layered or clotted specimen
- Blood can be applied outside of the circles if needed
  - *Blood still needs to be the same size of the circles*
- If specimen is not of good quality, recollect on another card at that time

Air Drying Specimens

- Do not touch other blood spots
- Keep away from direct heat and humidity
- No direct sunlight
- Do not store specimens in vehicles – hot/cold/humidity can affect results
- Horizontal – actual blood spots
- Elevate off surface– the card can absorb anything on the countertops
- Dry at least ***3 hours*** at room temperature before placing in envelope
- To avoid contamination of the filter paper – wear gloves and make sure the flap is closed

Spot Check Card

Sample Quality for Newborn Screening

Simple Spot Check – Excerpt from *Blood Collection on Filter Paper for Newborn Screening Programs; Approved Standard—Fifth Edition (LA4-A5)*

VALID SPECIMEN

Allow a sufficient quantity of blood to soak through to completely fill the preprinted circle on the filter paper. Fill all required circles with blood. Do not layer successive drops of blood or apply blood more than once in the same collection circle. Avoid touching or smearing spots.

INVALID SPECIMEN	POSSIBLE CAUSES
 1) Specimen quantity insufficient for testing.	• Removing filter paper before blood has completely filled circle or before blood has soaked through to second side. • Applying blood to filter paper with a capillary tube. • Allowing filter paper to come into contact with gloved or ungloved hands or substances such as hand lotion or powder, either before or after blood specimen collection.
 2) Specimen appears scratched or abraded.	• Applying blood with a capillary tube or other device.
 3) Specimen not dry before mailing.	• Mailing specimen before drying for a minimum of three hours.
 4) Specimen appears supersaturated.	• Applying excess blood to filter paper, usually with a device. • Applying blood to both sides of filter paper.
 5) Specimen appears diluted, discolored, or contaminated.	• Squeezing or "milking" of area surrounding the puncture site. • Allowing filter paper to come into contact with gloved or ungloved hands or substances such as alcohol, formula, antiseptic solutions, water, hand lotion, or powder, etc., either before or after blood specimen collection. • Exposing blood spots to direct heat.
 6) Specimen exhibits serum rings.	• Not allowing alcohol at the puncture site to air dry before making skin puncture. • Allowing filter paper to come into contact with alcohol, hand lotion, etc. • Squeezing area surrounding puncture site excessively. • Drying specimen improperly. • Applying blood to filter paper with a capillary tube.
 7) Specimen appears clotted or layered.	• Touching the same circle on the filter paper to blood drop several times. • Filling circle on both sides of filter paper.
 8) No blood.	• Failure to obtain blood specimen.

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Quick Guide

July 2007

www.clsi.org

CLINICAL AND LABORATORY STANDARDS INSTITUTE

Good Quality Specimen

- After collection, determine whether or not the specimen is acceptable
- Double check quality of your specimen once dried
- If unacceptable, recollect at that time on a new filter paper

Recollection

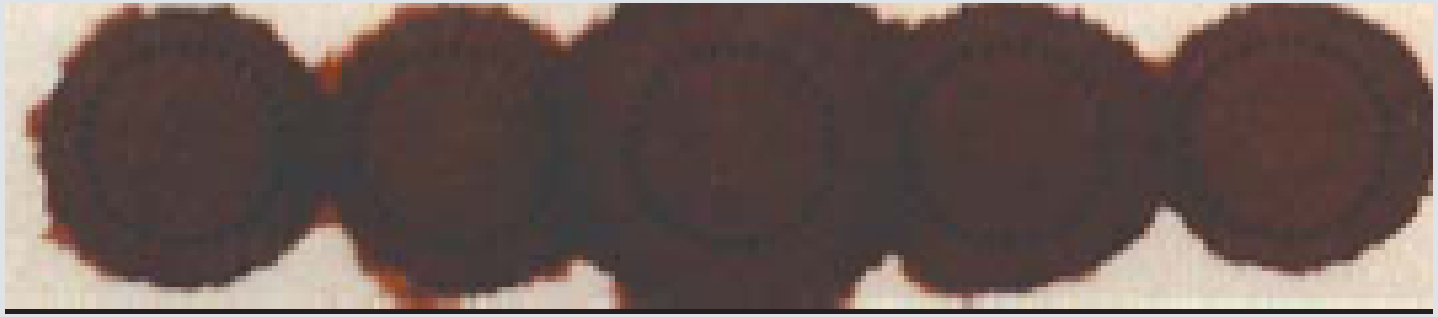
- *Collecting a good quality specimen the first time reduces the chance of having to recollect another specimen*

The NBS Was Rejected… Why?

- The NBS Program will reject a sample if
  - *Poor quality, e.g., insufficient amount of blood, contaminated sample, blood didn't soak through filter paper, expired collection form, layered, etc.*
- All samples are tested even if rejected

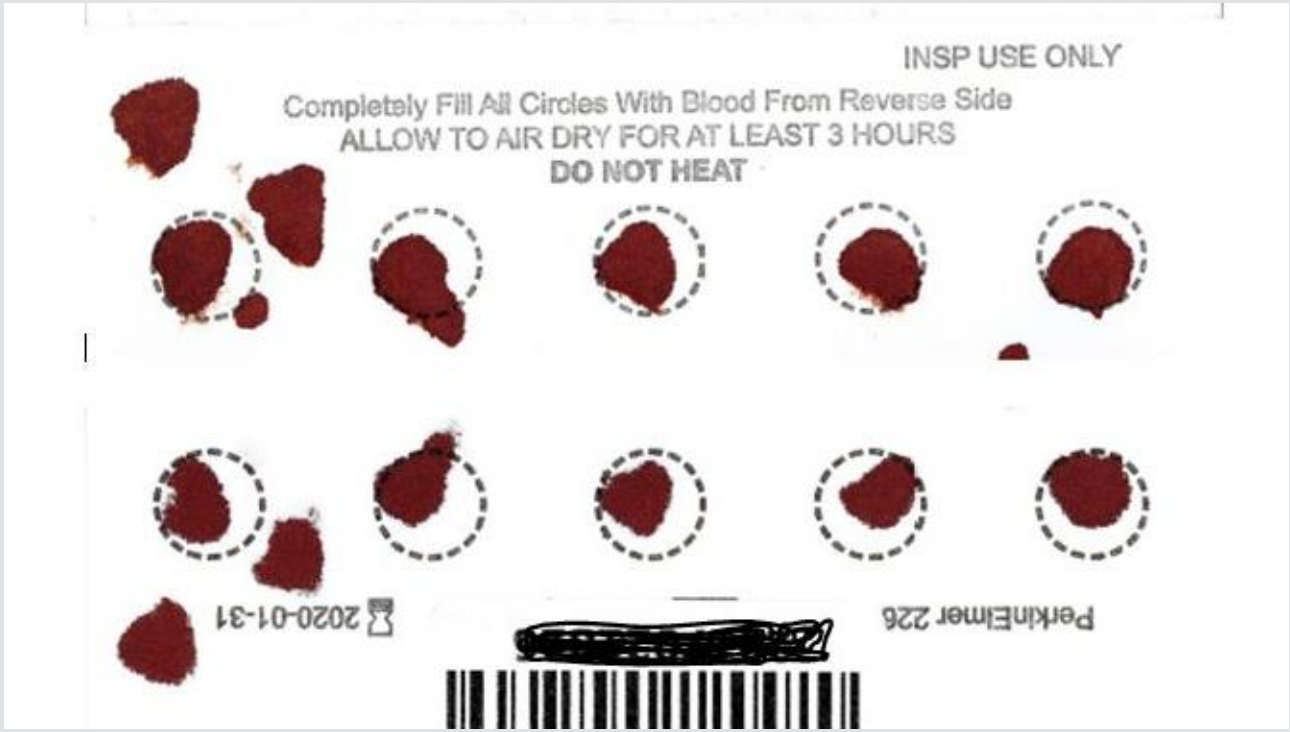
Too much blood

- Over-saturated

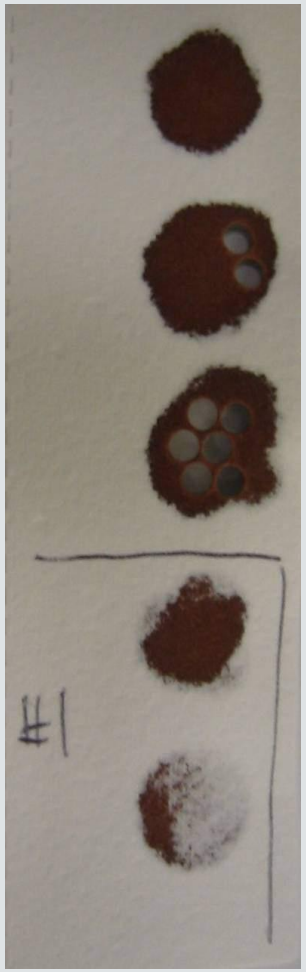


Insufficient blood

- Applying drops that are too small
- Removing filter paper before blood has soaked through to the other side



Uneven saturation



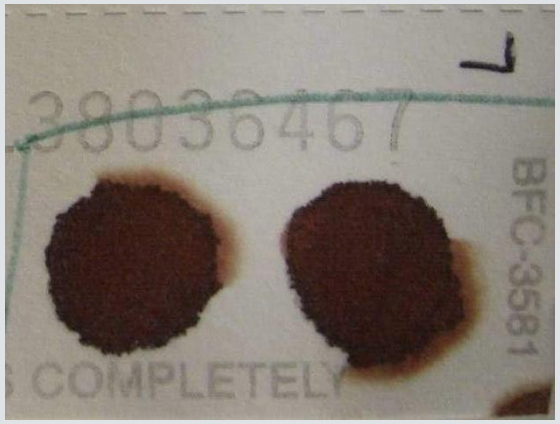
- Insufficient quantity so blood did not soak through
- Spreading the blood drop over the surface of the circle, contributing to uneven absorption.
- Improperly applying blood to the filter paper with a device.

Layering

- Multiple drops added to each circle
- Non-uniform concentrations
- Analyte concentrations are not consistent

Contamination or dilution

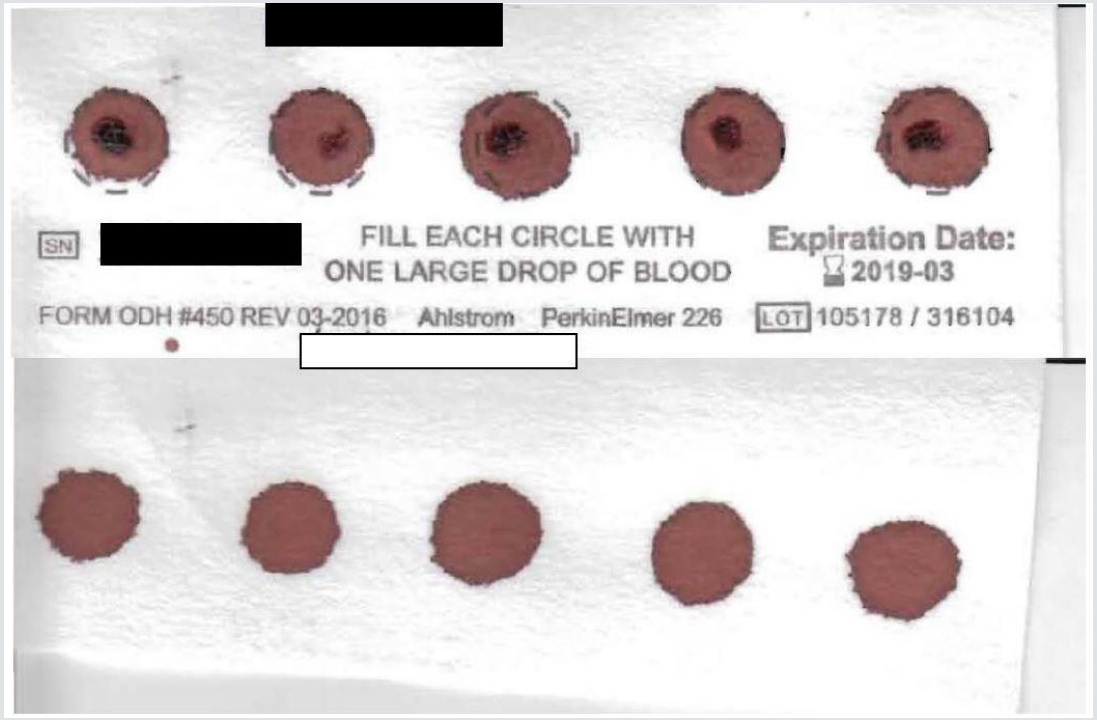
- Alcohol not dried on baby's heel
  - *Other fluid/substances*
- Substances on bench top
- Not always this noticeable
- May affect analysis



Blood didn’t soak through

Make sure to check the blood has soaked through on both sides

Clotted Specimen

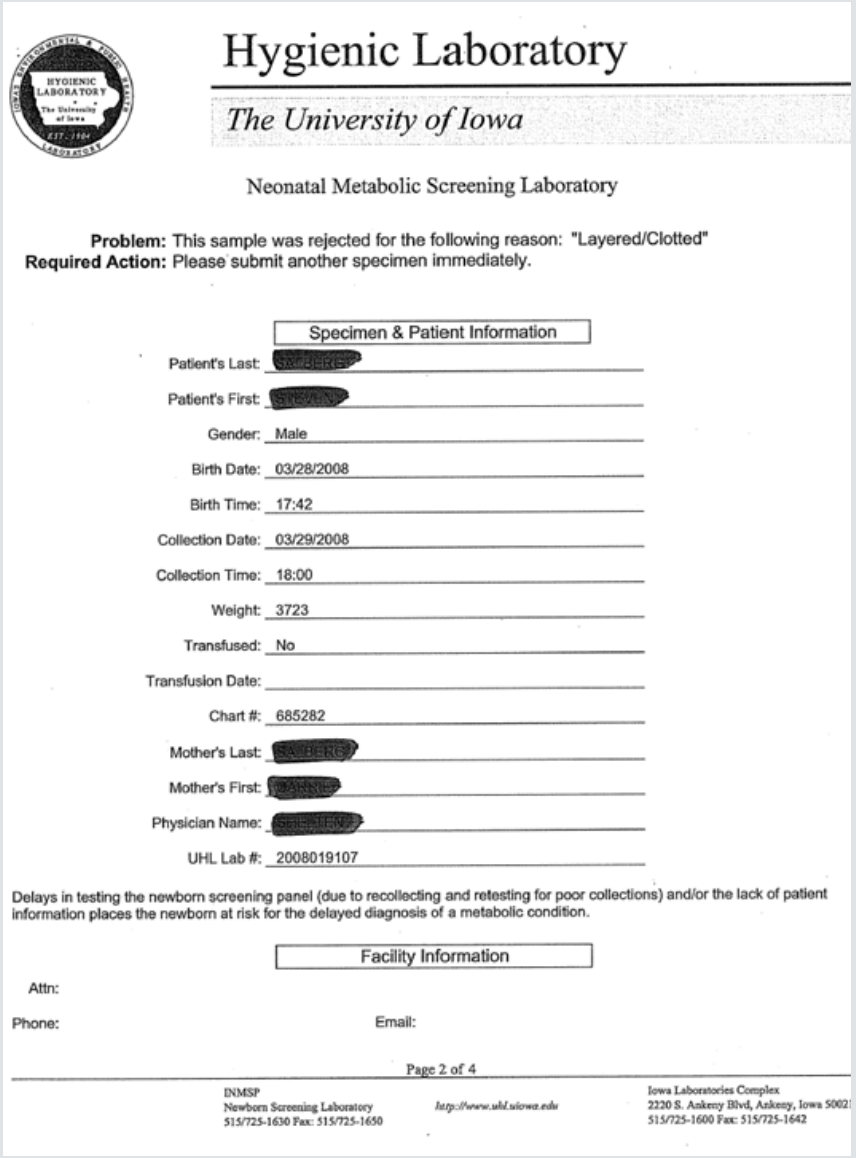


Serum separation

- Serum rings
  - *Squeezing or milking the heel causes hemolysis*
  - *Use gentle pressure*
  - *RBCs have settled in capillary tube*

Quality Assurance

- Daily fax sent from lab to collectors for missing information or poor quality specimens
- Must be a secure fax line
- Fill out necessary information and fax back immediately
- Does this work for you or what is the best way for us to reach you?



Hygienic Laboratory

The University of Iowa

Neonatal Metabolic Screening Laboratory

Problem: This sample was rejected for the following reason: "Layered/Clotted"
Required Action: Please submit another specimen immediately.

Specimen & Patient Information

Patient's Last: [redacted]
Patient's First: [redacted]
Gender: Male
Birth Date: 03/28/2008
Birth Time: 17:42
Collection Date: 03/29/2008
Collection Time: 18:00
Weight: 3723
Transfused: No
Transfusion Date:
Chart #: 685282
Mother's Last: [redacted]
Mother's First: [redacted]
Physician Name: [redacted]
UHL Lab #: 2008019107

Delays in testing the newborn screening panel (due to recollecting and retesting for poor collections) and/or the lack of patient information places the newborn at risk for the delayed diagnosis of a metabolic condition.

Facility Information

Attn:
Phone: Email:

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INMSP
Newborn Screening Laboratory
515/725-1630 Fax: 515/725-1650

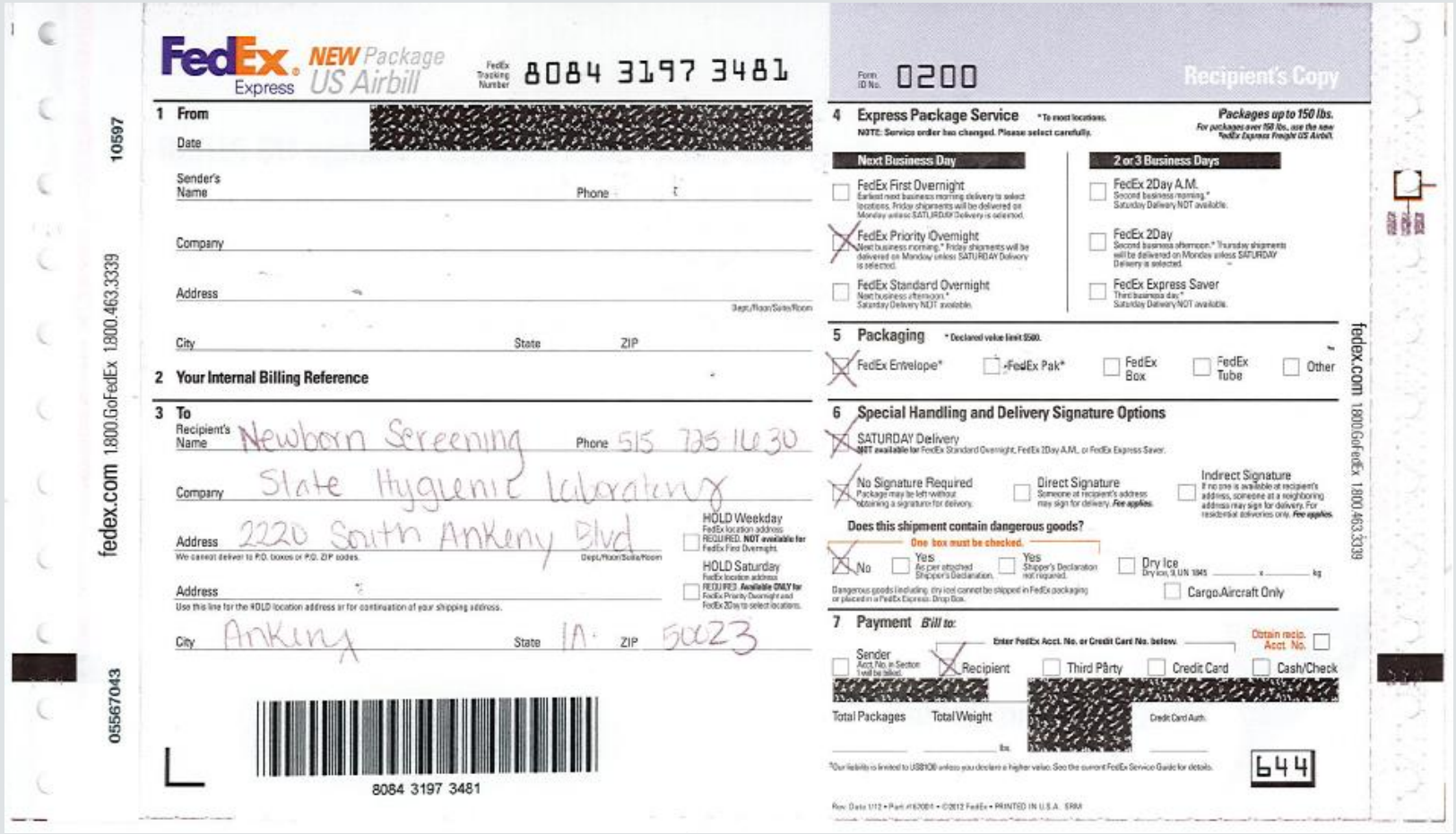
http://www.uhl.uiowa.edu

Iowa Laboratories Complex
2220 S. Ankeny Blvd, Ankeny, Iowa 5002
515/725-1600 Fax: 515/725-1642

Sending Specimens to the Laboratory

- Birthing facilities use a courier service for specimen transport to the lab – at no cost to the facilities
- Home births, Fed Ex overnight is recommended, you may also use UPS overnight
- Never place a specimen in the regular USPS mail – this may delay testing by 5-7 days

Example of Completed Fed Ex Label



- Contact Ashley Comer at the Iowa Lab for setting up shipping for your specimens – 515.725.1630

Desired Outcomes

- Specimens must be collected between 24-48 hours – ideally closer to 24 hours
- Specimens must be transported ASAP – ideally the same day as collection
- Presumptive Positive results for Time-Critical conditions are reported daily
- Appropriate information must be able to be provided to the baby's PCP every day, so that a baby with a Presumptive Positive for a Time-Critical condition can be evaluated on any given day

Every baby deserves the same opportunity for a healthy life regardless of which day they are born

Newborn Screening Results

Normal Results

- Health care provider will notify parents at the first well child visit (should be within the first few weeks of life)
- If the midwife is the provider, it is their responsibility to notify the parents of the results
- Midwife can download each babies report from the Iowa database
- Specimen collectors will receive a mailed copy of the results from the laboratory

Out of Range (Abnormal) Results

- Borderline/Presumptive Positive Results
  - *Reported to Health Care Provider listed on the card*
- Short-term follow-up staff are notified by the lab and contact is made with provider in < 1 hour
- Short-term follow-up fax a letter with recommendations to the provider after contact is made
- Recommendations vary depending on severity of each disorder:
  - *Repeat screening*
  - *Diagnostic/confirmatory testing*
  - *Examine baby urgently (ER or office)*
  - *Hospitalization locally or transfer to a tertiary health facility may be necessary*

Newborn Screening Report

State Hygienic Laboratory

The University of Iowa

NURSERY SUPERVISOR	For Questions About Resubmission and Result Interpretation Contact Medical Consultants
	For Questions about resubmission and results, referrals, and newborn screening procedures, contact the North Dakota Health Department, Joyal Meyer 701-328-4534.

Newborn Screening Report

Patient		Birth Date	
Chart Number		Date Collected	
Mother's Name		Date Received	
Physician		Early Collection	
Laboratory No.		Transfused	
Test		Weight at Collection	
Date Reported		Gender	

Disorder	Substance(s) Measured	Result Interpretation
Congenital Adrenal Hyperplasia	17-Hydroxy Progesterone	Within Normal Limits
Hypothyroidism	Thyroid Stimulating Hormone	Within Normal Limits
Biotinidase Deficiency	Biotinidase	Within Normal Limits
Galactosemia	Gal-1-Phosphate Uridyl Transferase	Within Normal Limits
Hemoglobinopathies	Hemoglobin Phenotype	Within Normal Limits
Cystic Fibrosis	Immunoreactive Trypsinogen	Within Normal Limits
Expanded Screening Disorders	Amino Acids and Acylcarnitines	Within Normal Limits
Severe Combined Immunodeficiency	T-Cell Receptor Excision Circle	Within Normal Limits

Expanded Screening Disorders: Analytes Screened: Analytes refer to amino acids: (ARG) Arginine, (ASA) Argininosuccinic Acid, (CIT) Citrulline, (LEU) Leucine, (MAA) Multiple Amino Acids, (MET) Methionine, (PHE) Phenylalanine, (SA) Succinylacetone, (TYR) Tyrosine, (VAL) Valine and acylcarnitines: LOW C0, HI C0, C3, C3-DC, C4, C4-DC, C4-OH, C5, C5:1, C5-DC, C5-OH, C6, C6-DC, C8, C10, C10:1, C14, C14:1, C16, C16-OH, C16-OH/C16, C16:1-OH, C0/C16, C18:1, C18-OH, C18:1-OH, (MAC) multiple acylcarnitines.

This is a screening test and not indicated for stand-alone purposes; results should be used in conjunction with other available laboratory and clinical information. A false negative or a false positive result must always be considered when screening; therefore, clinical findings and status should be considered whenever interpreting laboratory results. Newborn reference values may not be applicable to older infants, thus screening results should be interpreted with caution in such cases. Disorder information is available in the Practitioners' Manual at www.idph.state.ia.us/genetics.

INMSP
Newborn Screening Laboratory
515/725-1630 Fax: 515/725-1650

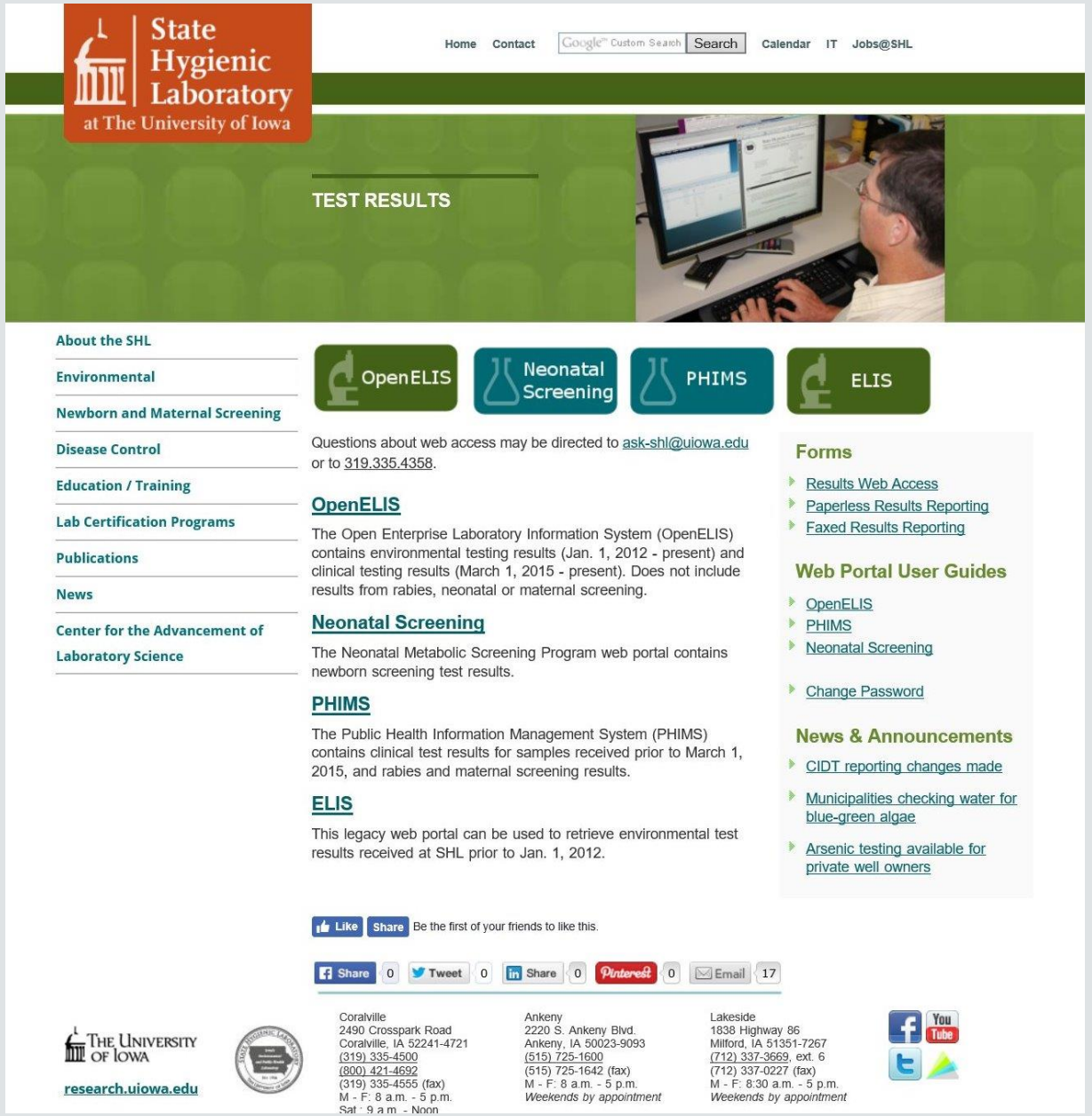
http://www.shl.uiowa.edu

Iowa Laboratories Complex
2220 S. Ankeny Blvd, Ankeny, Iowa 50021
515/725-1600 Fax: 515/725-1642

State Hygienic Laboratory (SHL) Database

Advantages of Database Web Access

- Download and print patient results
- Patient look-up online
- NBS reports available as soon as released by lab
- Reports available for your facility
  - *Quality control*
  - *Turnaround Statistics (ie. birth to collection, birth to reported etc.)*
  - *Facility Summary*
  - *Facility QA*
- Track unsatisfactory specimens back to collector
- www.shl.uiowa.edu



SHL Database Web Access

- Request permission for web access through the NBS Program Director
- Request is sent to the Iowa laboratory IT Department
- Once approved, you will be given a unique user id and password
- Training via phone from Iowa IT on how to use web access (approximately 10 minutes)
- Login to access database:
  - *www.shl.uiowa.edu*

Reminder - It's a Screening Test

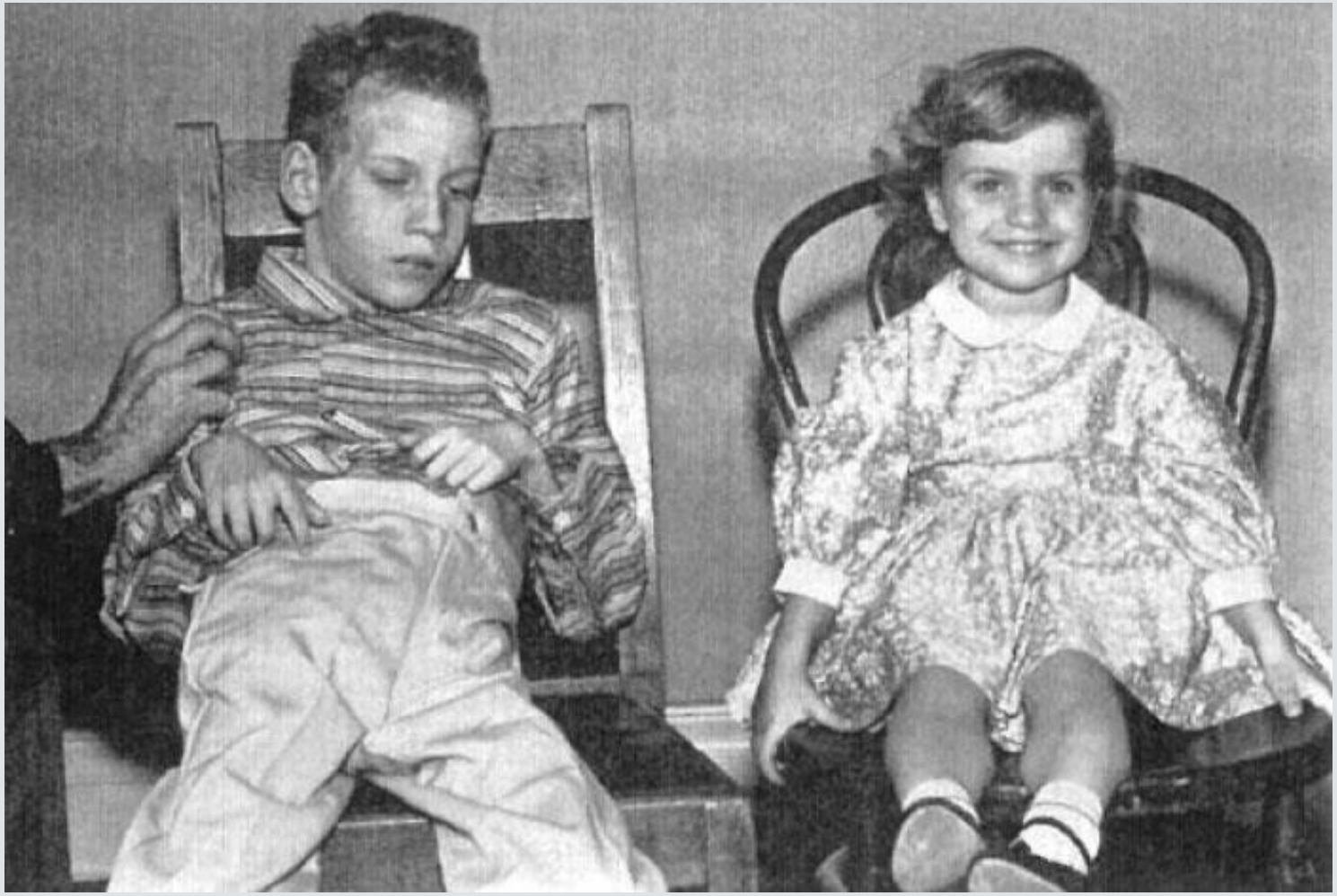
- DON'T PANIC

- Newborn screening is a screening test – not a diagnostic test
  - *It is important to follow the recommendations given by newborn screening follow up staff to confirm diagnosis*

- There may be false positives/false negatives
  - *The NBS program is involved in constant quality improvements/refinements to decrease false positives and false negatives*

- Continuously improving and evolving practice and testing

PKU Before Newborn Screening



Jack Chapman

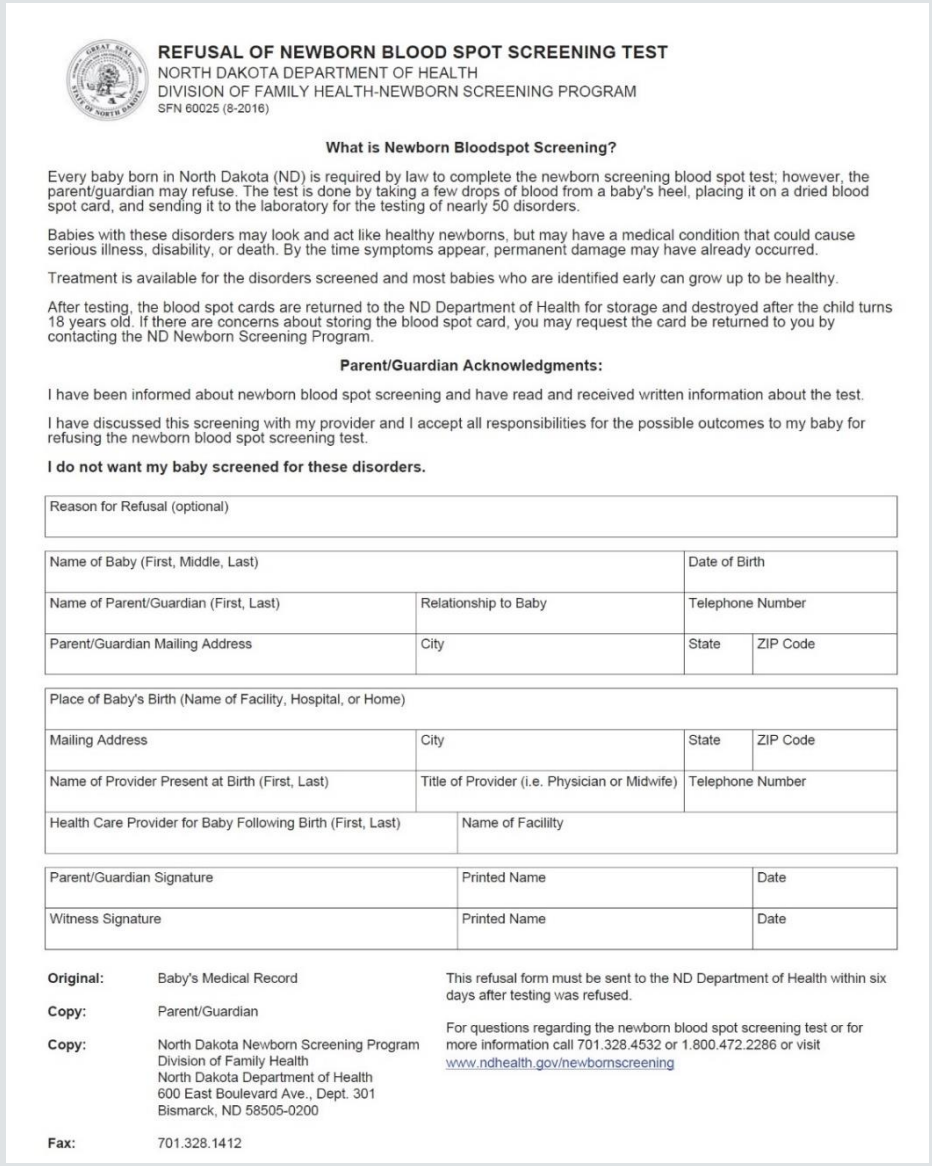
Jack's Newborn Screening Story

- Jack was 4 days old when his mother received a call from his pediatrician saying that Jack's NBS was abnormal.
- Jack was 6 days old when he was diagnosed with MCAD – a time critical disorder – that can suddenly cause death to a baby when their blood sugar gets too low. They cannot convert fat into energy.
- Because everything went well in the screening and follow up process, Jack's parents knew to feed him frequently (every 2-3 hours) to avoid low blood sugar.
- Although Jack will need to avoid fasting and eat a low fat diet throughout his life, he should lead a perfectly normal, healthy life.

Prenatal Education for Newborn Screening and Your role as the Collector

- Education prior to delivery decreases anxiety levels for parents
  - *Research shows that the postpartum period is not the best time to introduce newborn screening education*
- Allows parents to make an informed decision
- Help parents understand the importance of NBS – they will be more likely to follow up in a timely manner if their baby needs further testing
- Respond quickly to requests from NBS follow up or lab & follow recommendations
- Review normal results with parents at the first check up – they want to know
- What current education are you providing on newborn screening for your patients?

Newborn Screening Refusals



REFUSAL OF NEWBORN BLOOD SPOT SCREENING TEST
NORTH DAKOTA DEPARTMENT OF HEALTH
DIVISION OF FAMILY HEALTH-NEWBORN SCREENING PROGRAM
SFN 60025 (8-2016)

What is Newborn Bloodspot Screening?

Every baby born in North Dakota (ND) is required by law to complete the newborn screening blood spot test; however, the parent/guardian may refuse. The test is done by taking a few drops of blood from a baby's heel, placing it on a dried blood spot card, and sending it to the laboratory for the testing of nearly 50 disorders.

Babies with these disorders may look and act like healthy newborns, but may have a medical condition that could cause serious illness, disability, or death. By the time symptoms appear, permanent damage may have already occurred.

Treatment is available for the disorders screened and most babies who are identified early can grow up to be healthy.

After testing, the blood spot cards are returned to the ND Department of Health for storage and destroyed after the child turns 18 years old. If there are concerns about storing the blood spot card, you may request the card be returned to you by contacting the ND Newborn Screening Program.

Parent/Guardian Acknowledgments:

I have been informed about newborn blood spot screening and have read and received written information about the test.

I have discussed this screening with my provider and I accept all responsibilities for the possible outcomes to my baby for refusing the newborn blood spot screening test.

I do not want my baby screened for these disorders.

Reason for Refusal (optional)			
Name of Baby (First, Middle, Last)		Date of Birth	
Name of Parent/Guardian (First, Last)	Relationship to Baby	Telephone Number	
Parent/Guardian Mailing Address	City	State	ZIP Code
Place of Baby's Birth (Name of Facility, Hospital, or Home)			
Mailing Address	City	State	ZIP Code
Name of Provider Present at Birth (First, Last)	Title of Provider (i.e. Physician or Midwife)	Telephone Number	
Health Care Provider for Baby Following Birth (First, Last)	Name of Facility		
Parent/Guardian Signature	Printed Name	Date	
Witness Signature	Printed Name	Date	

Original: Baby's Medical Record

Copy: Parent/Guardian

Copy: North Dakota Newborn Screening Program
Division of Family Health
North Dakota Department of Health
600 East Boulevard Ave., Dept. 301
Bismarck, ND 58505-0200

Fax: 701.328.1412

This refusal form must be sent to the ND Department of Health within six days after testing was refused.

For questions regarding the newborn blood spot screening test or for more information call 701.328.4532 or 1.800.472.2286 or visit www.ndhealth.gov/newbornscreening

- Refusal form is available on the website
- Newborn screening is required by law in all 50 states; however, parents can object to testing
- "Written information" *must* be provided to the family before they can refuse
- Refusal form must completed, signed, and returned to the program within 6 days of refusing testing
- What are some reasons as to why some of your families refuse newborn screening?
- What can we do to help them understand the importance of testing and decrease home birth refusals?

Top 10 Things Parents Need to Know About NBS

1. Testing is required
2. Newborn screening saves lives
3. Babies with disorders may look healthy at birth
4. These disorders are not very common
5. These disorders can happen in families with no history of diseases
6. Treatment is available for ALL the disorders screened for
7. Just a few drops of blood
8. Discuss results with your health care provider
9. Retesting
10. Storage

Parent's Role in Newborn Screening

- Parents want to know about newborn screening
  - *Some parents are uninformed and often don't even know the testing was done or may refuse testing when they really don't understand what they are refusing*
- Make sure testing is done on their baby between 24 – 48 hours after they are born
- Ensure their most current contact information is on the blood spot card
- Ask for the results – inform them that no news isn't always good news
- Bring the baby in for repeat screens and/or confirmatory testing when requested in a timely manner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A BABY'S FIRST TEST -
THE ANSWERS MIGHT
SAVE A LIFE
Newborn Screening
is a test done before you leave the hospital using a few drops of blood from your baby's heel to screen for certain rare, but serious disorders. Babies with these disorders may look and act like healthy newborns, but may have a medical condition that could cause disability or even death. Most babies with these conditions who are identified within the first few days of life can receive treatment and grow up to be healthy and have normal development.
Ask your health care provider about newborn screening.
North Dakota
Newborn Screening Program
NORTH DAKOTA DEPARTMENT of HEALTH
OTW©2015

Not Screening?

a simple test can save your baby's life.

ASK YOUR HEALTHCARE PROVIDER ABOUT NEWBORN SCREENING TODAY

North Dakota Newborn Screening Program

NORTH DAKOTA DEPARTMENT of HEALTH

Contact Information

Mike Ramirez, Lab Supervisor, Iowa Laboratory

515.725.1630

Order supplies (DBS forms & drying racks)

515.725.1630

Questions on Specimen Transport – Ashley Comer

515.725.1630 or ashley-comer@uiowa.edu

Iowa State Hygienic Laboratory Database Issues (web access)

319.335.4358

University of Iowa Children's Hospital (patient short-term follow-up)

866.890.5965

Joyal Meyer, Newborn Screening Program Director, ND Department of Health

701.328.4534 or jbmeyer@nd.gov

Katie Bentz, Newborn Screening Nurse Consultant, ND Department of Health

701.328.4538 or kbentz@nd.gov

Kelsie Morris, Newborn Screening Administrative Assistant, ND Department of Health

701.328.4532 or kelsiemorris@nd.gov

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Questions